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ABSTRACT

Informed consent is required from a child's parent or guardian before use of some types of behavior modification for severe behavior problems, such as tantrums, self-abuse, aggression, stealing, destruction of property, etc. Behavior modification procedures that produce physical or psychological discomfort or pain require informed consent because they intrude on the person's body or mind. Both a legal and a practical definition of informed consent are offered, along with examples of informed consent used in special education settings. A legally valid consent must meet the three criteria of being voluntary, knowledgeable, and intelligent. An informed consent document should be completed by parents/guardians to give legal permission for educators to carry out an intrusive treatment. The document should include a description of the problem behavior, previous treatments, proposed treatment, risks of proposed treatment, type of data collected and data collection methods, expected outcomes, treatment implementor, alternative treatments, and the parents' consent. This guide for educators and parents is written in a programmed instruction format, with review questions following presentation of each brief section of material. (JDD)

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Behavioral Treatment and Review System

Informed Consent for Intrusive Behavioral Treatments

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SECTION I

INTRODUCTION

Informed Consent

Introduction

This set of materials is for educators and parents who are concerned with children who have severe behavior problems. These behaviors might include serious tantrums, self-abuse, aggression, stealing, destruction of property, etc. The focus of these materials will be on the concept and procedures of informed consent for treatment of serious behavioral problems.

One of the most respected systems for treating severe problem behaviors is behavior modification. Teachers who use behavior modification for severe behavior problems may use techniques with names such as time-out, facial screening, overcorrection, restraint, and required relaxation. These techniques have been regulated by courts and legislatures. In order to use these treatments, you should know about the laws that govern them.

One set of relevant laws concerns the idea of informed consent. Simply put, if you want to use a behavior modification technique such as any of those just mentioned, you need to get legal permission from the child's parent or guardian. This legal permission is usually called "informed consent."

Here are a couple of questions. Choose the answer that you think is correct for each one.

Question 1) To use behavior modification for severe behavior problems, you must get _____ : (choose a, b or c)

a) a consent from a court

b) legal permission from parents

c) advice from a lawyer

The correct answer to the question is "b": you must get legal permission from parents to use behavior modification for severe behavior problems of a student.

Question 2) Another name for legal permission is: (choose, a, b or c)

a) informed consent

b) a court order

c) a consent decree

Legal permission is called "informed consent," so the correct answer is "a".

The following material will explain: 1) Why it is necessary to obtain informed consent; 2) What makes consent legally valid; 3) How to write a consent form; and, 4) How to include full informed consent within your IEP process.

SECTION II

WHAT IS INFORMED CONSENT AND HOW IS IT USED?

Introduction

This material describes why it is necessary to obtain informed consent before you use behavior modification methods with severe behavior problems. You will learn both a legal and a practical definition of informed consent, become familiar with some examples of informed consent, and learn why informed consent procedures are used.

Now let's look at some examples of informed consent in educational settings. This should help you get a sense of what informed consent means. Here is the first example: A teacher believes that a child who hits other children should be reprimanded and physically isolated from the class every time hitting occurs. The teacher explains this approach to the parents and asks them to sign a form that also provides an explanation. By signing the form, the parents give permission for the teacher to begin.

In this example, the teacher explains a proposed treatment for a child and asks the parents' permission to start. Is this an example of a teacher obtaining informed consent? Yes, it is an example of a teacher obtaining informed consent because it includes an explanation and signed permission.

Now here is a second example: A school psychologist believes that a child should be evaluated for special education placement. S/he wants to give an IQ test to the child. The district office sends a notifica-

tion to the parents which explains the parents' rights and the purpose of the test, and it asks the parents' permission for testing of the child.

Voluntary, Knowledgeable, Intelligent

Each of these examples involves informed consent. In these and in other similar cases, informed consent from parents or guardians must be voluntary, knowledgeable, and intelligent.

Must informed consent must always be voluntary, knowledgeable, and intelligent? Yes, to be valid, informed consent must always be voluntary, knowledgeable and intelligent.

According to the courts, informed consent means "a voluntary agreement by a person in possession and exercise of sufficient mentality and information to make an intelligent choice to do something proposed by another." In real English, this means that to get informed consent to do something to another person, you must make sure that you meet three conditions. These are that: 1) the person must give consent voluntarily; 2) the person must be knowledgeable about what such consent means; and, 3) the person must be capable of making an intelligent decision about giving consent.

Let's go over that one more time. To get full informed consent, you must be certain that any consent you acquire is voluntary, knowledgeable, and intelligent.

Here's another question for you.

What are the three (3) essential conditions of informed consent? (choose a, b or c)

a) voluntary, literate, capable

b) voluntary, knowledgeable, intelligent

c) voluntary, intelligent, motivated

The three essential conditions of informed consent are that it must always be voluntary, knowledgeable and intelligent, so "b" is the correct answer.

Informed consent first became a legal concern early in this century. The initial cases that required informed consent involved medical treatment. For example, in one case, a woman went into the hospital to have her appendix removed. During the surgery, the doctor found that her reproductive organs were diseased. The doctor removed them. The woman sued the surgeon and hospital. The courts found the hospital and doctor liable because the patient had not given consent.

In this case, the courts did not care whether or not the treatment was successful. They were concerned only with whether or not consent had been given.

Here is a question that will help you to check your understanding so far.

Is informed consent essential when a treatment is known to be very effective for a severe behavior problem? (answer "yes" or "no")

Informed consent is always required before you use a behavioral treatment for a severe behavior problem, so "yes" is the correct answer.

Constitutional Rights of People

The idea behind informed consent is that every person has a constitutional right to be in charge of what happens to his/her body. No one can legally intrude on another person's body or mind without consent. This idea was first defined in medical cases. It was then expanded to include other intrusive treatments including the use of mood altering drugs, electro-shock therapy, and certain kinds of behavior modification therapies. Behavior modification procedures that produce physical or psychological discomfort or pain require informed consent because they intrude on a person in a manner which is physical or psychological.

Here are some review questions.

Question 1) Is informed consent required only in medical cases?
(Answer "yes" or "no")

The answer is "no". Informed consent is required anytime someone uses an intrusive treatment with another person.

Question 2) Informed consent is required because of the _____:
(choose a, b or c)

a) constitutional rights of people

b) state laws of Oregon

c) professional ethics of educators

Informed consent is required because of the constitutional rights of people, so "a" is the correct choice.

Question 3) Some behavior modification procedures require informed consent because they _____: (choose a, b or c)

a) change people's behavior

b) intrude on people's body or mind

c) are not effective sometimes

Some behavior modification procedures require informed consent because they intrude on people's body or mind, so "b" is the correct choice.

Intrusive Behavior Modification Procedures

Behavior modification has been the subject of various court decisions. For example, the courts have determined the conditions under which institutional staff may use restraints on a severely handicapped person who is involved in self-injury. The courts have also established standards for the use of time-out and other intrusive treatments with institutionalized retarded persons.

As a result of the cases described above and other similar ones, guidelines about the use of behavior modification have emerged. The courts have ruled that full informed consent is required when intrusive behavior modification procedures are used. "Intrusive" procedures are those that might cause physical or psychological pain or discomfort.

Here are two more questions for you.

Question 1) Informed consent is required when behavior modification procedures are: (choose a, b or c)

a) ineffective

b) insensitive

c) intrusive

The correct answer is "c". Informed consent is required when behavior modification procedures are intrusive.

Question 2) Are "intrusive" behavior modification procedures those that primarily invade the privacy of a person's home? (answer "yes" or "no")

The correct answer is "no" because intrusive behavior modification procedures are any that cause physical or psychological pain or discomfort.

Certainly there are no absolute definitions of which procedures are intrusive. You must use good judgement when deciding whether psychological or physical pain or discomfort are a possible result of a particular procedure. The standard used by the courts involves determining whether an adequate administrative process was used to arrive at the decision to start an intrusive procedure. We will cover that process in detail later. For now, just remember that intrusive procedures are those that might cause physical or psychological pain or discomfort.

Here are a couple more review questions for you.

Question 1) Are there are absolute standards for determining whether a certain behavior modification procedure is intrusive? (answer "yes" or "no")

You should have answered "no" because there are no absolute standards for determining whether a certain behavior modification procedure is intrusive.

Question 2) A very important aspect of using intrusive behavior modification procedures is to be certain that: (choose, a, b or c)

a) they have been specifically approved by the courts

b) an adequate administrative process is used

c) parents/guardians are present whenever they are used

It is important to have an adequate administrative process when using intrusive behavior modification procedures, so "b" is the correct answer.

Review

So far you have learned several aspects of informed consent. Let's review what you have learned up to this point. First, you now know that informed consent is a legal concept. It is the legal way that a person gives permission to other people to involve that person in something that might produce physical or psychological pain or discomfort.

You have also learned that the idea of informed consent is based on constitutional rights. Under our constitution, no person can invade or intrude on the body or mind of another person without legal permission or, in other words, informed consent.

You have also learned that informed consent is an important concept to know for educators who use behavior modification techniques. Informed consent is required from parents or guardians when intrusive behavior modification procedures are used. These are procedures that might produce physical or psychological pain or discomfort for those children. In addition, it is essential to have an adequate administrative process for deciding to use intrusive procedures.

Finally, you learned that three (3) conditions must be met when getting informed consent. These are that: 1) consent must be given voluntarily; 2) the person who gives the consent must be knowledgeable about what such consent means; and 3) that person must be capable of making an intelligent decision about whether or not to give consent.

Now let's check your new knowledge about the meaning of informed consent and why it is required in certain situations. Answer the following questions.

Question 1) Is informed consent a legal concept because of the constitutional rights of people? (answer "yes" or "no")

Informed consent is a legal concept because of the constitutional rights of people, so "yes" is the correct answer.

Question 2) Does the idea of informed consent relate primarily to situations where physical discomfort is a possibility? (answer "yes" or "no")

Informed consent must be obtained whenever physical or psychological pain or discomfort is a possibility, so the correct answer is "no."

3) When you get informed consent from someone, you must be certain that it is: (choose, a, b or c)

a) voluntary, desirable, confident

b) voluntary, capable, effective

c) voluntary, knowledgeable, intelligent

Informed consent must always be voluntary, knowledgeable and intelligent, so the correct answer is "c".

4) Having an adequate administrative process for deciding to use intrusive behavior modification procedures is: (choose a, b or c)

a) recommended

b) optional

c) essential

It is essential to have an adequate administrative process for deciding to use intrusive behavior modification procedures, so the correct answer is "c".

If you answered three of the four questions correctly, you are ready to proceed with learning how to be sure that any informed consent that you obtain is valid. If you answered fewer than three of the four questions correctly, you should read these materials again before proceeding on to new material.

SECTION III

MAKING CERTAIN THAT INFORMED CONSENT IS VALID

Introduction

Not all consent is acceptable in a court of law. Some kinds of consent have been held to be invalid by the courts. In order to be valid, informed consent must meet three criteria. These criteria are the same as the three conditions for informed consent that you learned in the first lesson.

To be valid, consent must be: voluntary, knowledgeable, and intelligent. Several court decisions have defined what each of these criteria means. In this second lesson you will learn what makes consent voluntary, knowledgeable, and intelligent.

Here is a question for you.

Is valid consent any consent that meets the criteria of voluntary, knowledgeable, and intelligent? (answer "yes" or "no")

Any consent that meets the criteria of voluntary, knowledgeable and intelligent is valid, so the correct answer is "yes".

Voluntary Consent

First let's learn about voluntary consent. For consent to be voluntary, parents or guardians must be clearly aware that: 1) no

coercion or threat is being applied to them; 2) consent may be withdrawn by them at any time; and, 3) alternative treatment approaches exist.

Here is another question for you.

Is consent voluntary if parents or guardians are aware that no threat is being made, consent may be withdrawn at any time, and alternative approaches exist? (answer "yes" or "no")

Consent is voluntary when parents or guardians are aware that no threat is being made, they may withdraw consent at any time, and alternative approaches exist, so the correct answer is "yes".

The first condition for consent to be voluntary is that a parent or guardian must give it without feelings of duress or coercion. A parent or guardian must be free to consider the facts without pressure. For example, you should not make statements such as "your child will probably be suspended from school if we don't start this treatment now."

In general, it should be clear to an outside observer that you gave parents a chance to make up their own minds without pressure. If you appear to have forced or pressured a parent to give permission, the consent may not be valid.

Here's another question for you.

Is pressuring a parent or guardian to give consent for a behavioral treatment acceptable if their child's behavior is harmful to others? (answer "yes" or "no")

Pressuring a parent or guardian to give consent is never acceptable, so the correct answer is "no".

A second condition of voluntary consent is that a parent or guardian must understand that s/he can withdraw consent at any time. In other words, the parents can change their minds anytime. They can withdraw consent verbally or in writing.

Parents should be told, in writing, that they can stop a treatment procedure at anytime. You may inform the parent of the risks of stopping the treatment, but must honor the parents' right to withdraw permission.

Here's a question for you.

Must parents or guardians be informed in writing that they may withdraw consent at any time for any reason and that treatment will stop if they withdraw consent? (answer "yes" or "no")

The correct answer is "yes". You must <u>always</u> inform parents in writing that they may withdraw consent at any time and that treatment will stop if they withdraw consent.

A final condition of voluntary consent is that, as much as possible, parents must be provided an explanation that <u>there are alternatives to the proposed treatment</u>, but that the proposed treatment is preferable. The reason for this is that when parents choose from different alternatives, they are making a voluntary choice.

Alternative treatments may include those available or possible in the current educational setting and in other settings such as private psychological or educational clinics or schools.

Here's an example of obtaining informed consent for treatment of a child who hits and hurts other children. You might propose an overcorrective exercise which requires the child who hits to move his/her arms up and down 50 times every time such physical aggression occurs.

In order to get voluntary consent, you would need to explain the treatment to the parents and explain alternatives available in the current setting (perhaps a time-out procedure) and in other settings (perhaps treatment by a private psychologist).

You would also need to explain why the proposed treatment is preferable (perhaps because it is known to work more quickly than the alternatives with most aggressive children and/or is less intrusive on the child than alternatives.)

You should never threaten expulsion or transfer when you explain alternatives. If a student really might be expelled or institutionalized if a behavior is not controlled, you need to let the parents know this possible outcome. You must also describe possible alternative treatment choices, even if they are known to be less effective than the proposed treatment.

Now answer the following two questions.

1) When parents are given descriptions of proposed and alternative treatments, their consent is more voluntary because: (choose a,b or c)

a) they are offered a choice

b) they are willing to listen

c) they propose the treatment

The correct answer is "a". Consent is more voluntary when descriptions of both proposed and alternative treatments are given because then parents have more of a choice.

2) Explanations of treatments should emphasize: (answer a,b or c)

a) proposed treatments

b) alternative treatments

c) both a and b

Explanations should emphasize both proposed and alternative treatments, so the correct answer is "c".

To be valid, consent must be voluntary, knowledgeable, and intelligent. So far in this lesson you have learned how to be sure that consent is <u>voluntary</u>. Let's review what makes consent voluntary. For

consent to be voluntary, parents or guardians must know that: 1) there is no coercion or threat; 2) They may withdraw consent at any time; 3) there are alternative treatments.

In other words, to provide voluntary consent, parents or guardians must feel no undue pressure, must be told in writing that they can change their minds about the proposed treatment, and must be aware of all reasonable alternatives.

Here are three questions to test how well you understand what constitutes voluntary consent.

1) Is consent voluntary as long as no threats are made to parents? (answer "yes" or "no")

The correct answer is "no" because consent is voluntary only if parents are aware that no threats exist, and they may withdraw consent at any time, and alternative treatments exist.

2) Must parents be told in writing that they may withdraw their consent at any time? (answer "yes" or "no")

Parents must always be told in writing that they may withdraw their consent at any time, so the correct answer is "yes".

3) Must parents be given explanations of alternative treatments even if those alternatives are known to be ineffective? (answer "yes" or "no")

Parents must be given explanations of alternative treatments even if those alternatives are known to be ineffective, so the correct answer is "yes".

If you answered all three of these questions correctly you should go on to the next section. If not, please review this section on "voluntary consent" before you go on.

Knowledgeable Consent

Good. Now you know what makes consent voluntary. Let's go on to learn about what makes consent knowledgeable. Informed consent must also be knowledgeable in order to be valid. To ensure that consent is knowledgeable, you must make your explanations understandable and comprehensive.

First, whenever you ask for informed consent, you must make your explanation understandable. To make a reasonable decision, parents or guardians must understand what they are deciding. You should avoid jargon and technical language.

For example, if you asked people to give permission to apply "subcutaneous electro-stimulation devices" above their "left anterior

mastoid," they could not make a reasonable decision if they did not understand the nature of the decision.

Another example from special education should be useful here. Although some special educators may be comfortable with terms such as "aversive", "contingent," "time-out," and "differential reinforcement," these words may not make sense to another person.

Here are a couple of questions for you.

1) When obtaining informed consent, you must provide an explanation which is: (choose a or b)

a) understandable to other professionals

b) understandable to parents

Explanations must always be understandable to parents, so the correct answer is "b".

2) Many parents will regard the phrase "overcorrective exercise" as: (choose a or b)

a) jargon

b) understandable

The phrase "overcorrective exercise" will be regarded as jargon by many parents, so the correct answer is "a".

Another element in making explanations understandable is that the explanations and the consent form which is to be signed should be in the parent's primary language. A parent whose primary language is Spanish may not understand English. You must get an interpreter to assist you if necessary.

For parents or guardians to be knowledgeable, explanations about proposed treatments must be understandable to them. Thus, in order to have valid informed consent, you will need to explain your proposed treatment clearly and in the parent or guardian's primary language.

Here are two review questions.

1) Why must explanations be understandable to parents or guardians about proposed treatments be in the parent or guardian's primary language? (choose a or b)

a) To be voluntary

b) To be understandable

Explanations about proposed treatments must be in the parent or guardian's primary language in order to be understandable so the correct answer is "b".

2) Can we assume that most parents or guardians will understand an explanation such as: "We will use a time-out procedure every time your child yells in class"? (answer "yes" or "no")

Some parents or guardians will not understand an explanation with the phrase "time-out" in it, so the correct answer is "no".

For consent to be knowledgeable the information provided to the parent must also be comprehensive. The four things which must be clearly explained for treatment information to be comprehensive are: 1) nature of treatment; 2) risks of treatment; 3) risks in not giving treatment; 4) likely outcome of treatment.

Let's take these four components of comprehensiveness one at a time. First, information provided to the parent must include a description of the nature or relevant circumstances of the treatment. The circumstances are often important in behavioral treatments.

For example, if a teacher is proposing to use time-out, s/he should describe where the student will go during time-out. The teacher might plan to have a student sit in the hallway during such a time-out. The parent should be told that the hallway can be quite cold (if indeed such is the case).

In this example, the temperature of the hallway is a relevant circumstance. Without this information, the parent is not fully knowledgeable and cannot judge the severity of the treatment.

Here's another question for you.

Is the first element of comprehensive explanations to parents or guardians a general description of the nature of the treatment? (answer "yes" or "no")

The first element of comprehensive explanations to parents or guardians is a general description of the nature of the treatment, so the correct answer is "yes".

To be comprehensive, information provided to parents must also include a description of the risks involved in the treatment. A teacher should consider any possible negative results of a treatment. For example, when using physical restraint there is some danger that a student will be bruised.

When you use time-out, a student might miss important instructional time. When overcorrective exercise is used the student might get used to the exercise and become stronger and more difficult to manage. When using any intrusive procedures to eliminate behaviors, there is a risk that the problem will temporarily get worse.

The teacher should explain all such possible risks to parents when asking for consent. Remember that all explanations should be in simple language, and free of jargon and technical language.

Here's another question for you.

Is it necessary to describe to parents or guardians the risks involved in a treatment? (answer "yes" or "no")

One element of comprehensive explanations to parents is a description of risks involved in the treatment, so the correct answer is "yes".

Comprehensive information also includes an explanation of the risks in not giving treatment. When asking for consent, the teacher should tell the parents the likely outcomes if the treatment is not given. It is important not to exaggerate and make statements that might appear to be a pressure tactic.

For example, a teacher might seek consent to use an intrusive treatment to teach a young student to stop slapping himself on the face. The teacher might describe a restraint technique in simple language. S/he would need to explain that there is some risk that the student might learn to like the restraint and that the behavior might temporarily get worse.

S/he would also explain that unless the slapping behavior is controlled, there is some risk that the student will bruise and injure himself. The parent can then make a more knowledgeable decision about the treatment when s/he can consider these risks of treatment and non-treatment.

Here are a couple of questions for you.

1) Is it necessary to provide a description of the risks if a treatment is not given? (answer "yes" or "no")

Because one element of comprehensive explanation is a description of the risks if a treatment is not given, the correct answer is "yes".

2) Can teachers describe the risks involved in not giving certain treatments in order to pressure parents to give consent? (answer "yes" or "no")

It is never acceptable to pressure parents to give consent, so the correct answer is "no".

Finally, to be comprehensive, information about treatments must also include an explanation of likely outcomes of the treatment. If a treatment will require ongoing procedures to maintain behavior change, these should be explained. If a treatment is likely to reduce a behavior but not eliminate it, this likelihood should be explained.

For example, a teacher might plan to use a time-out procedure to reduce a child's screaming. The teacher would explain that the treatment is likely to cut down the frequency of screaming but not completely eliminate it.

In descriptions of likely outcomes of a treatment, you do not need to worry that you must predict the future.. Instead you should make a good faith effort, based on your experience and knowledge of the behavioral literature, to state what you believe will happen.

Here is a question for you.

Must information given to parents or guardians about treatments include a description of likely outcomes of treatment? (answer "yes" or "no")

To be comprehensive, treatment information must include a description of likely outcomes of treatment, so the correct answer is "yes".

Now let's review all four of the elements of comprehensive explanations. Remember, all explanations of treatments must include clear descriptions of the following four things about treatments: 1) the nature or relevant circumstances; 2) risks in treatment; 3) risks in not giving the treatment; 4) likely outcomes of treatment.

Here's a question for you.

If a teacher describes the nature and likely outcomes of treatment, will that be a comprehensive explanation? (answer "yes" or "no")

To be comprehensive, treatment explanations must include descriptions of nature and likely outcomes of treatment, as well as descriptions of risks of treatment and no treatment, so the correct answer is "no".

This lesson has described what makes consent knowledgeable. To review briefly, for consent to be knowledgeable, two major standards must be met. Explanations to parents or guardians must be both understandable and comprehensive.

First, all explanations must be understandable. This means that the treatment must be explained in simple language that is generally free of jargon and technical terms.

Second, the information must also be comprehensive or complete. It should include a description of the important circumstances of the treatment, the risks of the treatment, the risks of non-treatment, and the likely outcome of the treatment.

Here are two review questions for you.

1) The two standards for consent to be knowledgeable are that: (answer yes" or "no")

a) explanations must be understandable and comprehensive

b) explanations must be technical and thorough

For consent to be knowledgeable, explanations must be understandable and comprehensive, so the correct answer is "a".

2) The elements of a comprehensive explanation are descriptions of: (choose a, b or c)

a) risks of treatment and non-treatment

b) nature and likely outcomes of treatment

c) both a and b

A comprehensive explanation contains descriptions of risks of treatment and non-treatment as well as nature and likely outcomes of treatment, so the correct answer is "c".

If you answered both of these questions correctly, go on to the next section. If not, please review this section on comprehensiveness of explanations to obtain informed consent.

Intelligent Consent

Excellent! Now that you know what makes consent voluntary and knowledgeable, you will learn how to be sure that consent is intelligent. For consent to be intelligent, it must come from a competent person who makes a rational decision.

Here is a question for you.

To be intelligent, consent must come from a person who is: (choose a, b or c)

a) competent and rational

b) intelligent and informed

c) both a and b

Intelligent consent must come from a competent and rational person, so the correct answer is "a".

Now let's define what makes a person competent to give consent. The courts have not provided simple, clear standards for determining the competence of a person for giving informed consent. But, if you follow three guidelines, you will be complying with the legal standards that exist.

The three guidelines for determining competence are that the person giving consent must: 1) be 18 years of age of older; 2) have a responsible role or relationship with the student (e.g. parent, guardian, "responsible" older sibling or other person, foster parent); and, 3) be intellectually and emotionally capable of understanding explanations and providing consent.

Here's a question for you.

Are the three guidelines for determining the competence of a person giving consent that the person must: 1) be 18 years of age or older; 2) have a responsible role with the student; 3) be intellectually and emotionally capable? (answer "yes" or "no")

A person giving competent consent must be 18 years of age or older, have a responsible role with the student and be intellectually and emotionally capable, so the correct answer is "yes".

Now let's go through these three guidelines for determining competence in more detail. The first, that the person must be 18 or older is self-explanatory. Simply put, to be competent to give consent, a person must be 18 or older.

The second guideline for determining competence is that the person giving consent must have a responsible role or relationship with the student. The courts and laws have not established a clear definition of a "responsible role or relationship." Obviously, parents and legal guardians have such roles. Some students, however, live with other persons without legal guardianship being established.

When it is clear that parents or guardians do not make day-to-day decisions for students, you may obtain informed consent from persons who function as major decision-makers for the student. For such persons to provide legal consent, they must acquire temporary or limited guardianship status. Check with your state Developmental Disabilities Division to find out the procedures to follow to do this. You should not obtain informed consent nor start intrusive treatments until temporary guardianship is established.

Here are a couple of questions for you.

1) Are parents or legal guardians the only persons who can give informed consent for intrusive behavioral treatments with students? (answer "yes" or "no")

People other than parents or guardians may give consent if temporary or limited guardianship is established, so the correct answer is "no".

2) When is it acceptable to obtain informed consent from someone other than a parent or legal guardian? (choose a or b)

a) only when parents or legal guardians are not immediately available

b) only when another adult is established as a temporary or limited guardian

Informed consent may be obtained from someone other than a parent or guardian only if another adult is established as a temporary or limited guardian, so the correct answer is "b".

The final guideline for determining the competence of a person giving consent is that the person must be intellectually and emotionally capable of understanding explanations and providing consent. Again, the courts and laws have not established absolute definitions of what makes a person intellectually and emotionally capable.

In general, consent is acceptable from any parent or guardian who has not been declared as incompetent in a formal court proceeding. However, some caution should be used in obtaining consent from persons who appear to be disabled by some degree of mental retardation or psychological disturbance.

A useful procedure in such cases is to have a third person present in addition to the parent or guardian when explanations are provided and

consent is requested. That other person should be independent of the school system and have some role in the student's life (for example, a social service case worker or an adult relative).

This person can act as a witness to the adequacy of all consent procedures and as to whether or not the parent or guardian understood what was being proposed, requested and signed.

The idea behind using such caution is that, if a parent or guardian is intellectually or emotionally disabled, any consent could be invalid because of lack of understanding on the part of the parent or guardian. Having another responsible person as a witness demonstrates your efforts to be certain that all conditions for informed consent are met in such cases.

Please answer the following review questions about competency of persons who give consent.

1) To provide valid consent, must a parent or guardian be intellectually and emotionally capable of understanding explanations? (answer "yes" or "no")

To provide valid consent, a parent or guardian must be intellectually and emotionally capable of understanding explanations, so the correct answer is "yes".

2) Have the courts have provided clear definitions of intellectual and emotional capability? (answer "yes" or "no")

The courts have not provided clear definitions of intellectual and emotional capability for giving consent, so the correct answer is "no".

3) What is the purpose of having another person present when explanations are given to a parents or guardians who are intellectually or emotionally disabled? (answer a, b or c)

a) to urge the parent or guardian to give consent

b) to witness the adequacy of explanations

c) both a and b

The purpose of having another person present is to have them witness the adequacy of explanations, so the correct answer is "b".

If you have answered all three of these questions correctly go on to the next section. If not, please review this section on competency of persons giving consent before going on.

O.K. You just learned that: 1) to be valid, consent must be "intelligent"; 2) one element of "intelligent" consent is competence of the person giving consent; and 3) there are three guidelines to use to determine the legal competence of a person to give informed consent. These three guidelines are that the person giving consent must: a) be 18

years of age or older; b) have a responsible role or relationship with the student; and c) be emotionally and intellectually capable of understanding the decision. Now let's see how well you remember what you just learned.

Please answer the following review questions regarding what makes consent "competent".

1) To be competent to give informed consent, must a person be a relative of the student? (answer "yes" or "no")

The correct answer is "no" because any competent adult who is the legal parent or guardian or who has established temporary or limited guardianship may give informed consent.

2) Have the courts have determined exactly who may provide consent? (answer "yes" or "no")

The courts have not clearly determined who may provide consent, so the correct answer is "no".

3) Must a person must be 18 or older to provide competent informed consent? (answer "yes" or "no")

A person must be 18 or older to provide competent informed consent, so the correct answer is "yes".

4) As long as a parent or guardian has not been declared incompetent in a formal court proceeding, should s/he be considered competent to provide informed consent? (answer "yes" or "no")

Parents who appear not to be emotionally/intellectually capable of understanding an explanation may not be competent to provide consent, so the correct answer is "no".

If you answered three of these four questions about competency correctly, go on to the next section. If not, please review the material you just covered on the first two elements of "competent consent."

Very good. Now let's cover the final element of competence, which is that the person giving consent must be making a rational or reasonable choice.

Again, no clear legal definitions exist as to what constitutes "rational" or "reasonable" choices by parents or guardians. In general, the courts ask if the decision is based on clear understanding and is one that a reasonable person would make in similar circumstances.

For example, a teacher might ask a parent for permission to use "overcorrective exercise" as a treatment. The teacher might propose to require a student to run 30 yards whenever the student screams inappropriately.

If the parent replies, "Yes, you can do that because that will get rid of all that energy in him," that reply would show that the parent does not understand what is being proposed and is not making a reasonable choice.

Thus, the parent is not giving "competent" consent; such consent would be invalid because it would not be "intelligent." It would not be "intelligent" because it would not be "rational." In such a case the teacher or school district may need to make extra efforts to obtain consent, such as further explanation or asking another responsible person to be present during informed consent procedures.

In most cases, consent is likely to be intelligent if the treatment is explained clearly and simply. Most parents or guardians will understand a treatment proposal if there is a clear explanation. As you can see, this element of determining whether consent is intelligent overlaps considerably with the elements in determining whether consent is knowledgeable.

Here are a couple of review questions for you.

1) To be "intelligent," consent must be: (answer a, b or c)

a) rational

b) reasonable

c) both a and b

To be "intelligent", consent must be both rational and reasonable, so the correct answer is "c".

2) A rational or reasonable choice is one that is based on clear understanding and is one that a reasonable person would make in similar circumstances. (answer "true" or "false")

A rational or reasonable choice is one based on clear understanding and one that a reasonable person would make in similar circumstances, so the correct answer is "true".

Great. Now you know what makes informed consent intelligent. Right? Right! Let's review. To be intelligent, consent must come from a person who is competent and who makes rational or reasonable choices.

Now answer the following questions.

1) To be valid, must consent be "intelligent"? (answer "yes" or "no")

To be valid consent must be "intelligent", so the correct answer is "yes".

2) Consent is "intelligent" if it comes from a person who is: (choose a, b or c)

a) competent and intelligent

b) intelligent and rational

c) rational and competent

Consent is intelligent if it comes from a person who is rational and competent, so the correct answer is "c".

3) Competence is determined by: (choose a or b)

a) age, relationship with student, mental capability

b) age, degree of family relationship to student, intelligence

Competence is determined by age, relationship with student and mental capability, so the correct answer is "a".

4) Should any consent provided by a parent or guardian be considered reasonable if a comprehensive, clear explanation has been given. (answer "yes" or "no")

A parent or guardian who shows signs of serious emotional or intellectual problems may not be capable of "intelligent" consent, so the correct answer is "no".

If you answered <u>three</u> of these four questions correctly, you have completed these materials on "What Makes Consent Valid?" If not, please review the final section which explains how to assure that consent is "intelligent".

SECTION IV

THE INFORMED CONSENT DOCUMENT

Informed Consent

Introduction

This section of these informed consent materials will describe the contents of an informed consent document. The informed consent document is a simple method for parents and guardians to give legal permission for educators to carry out an intrusive treatment. The completed informed consent document should be attached to the student's I.E.P. and it should be discussed at the annual I.E.P. meeting.

Here is a question for you.

Does the informed consent form: (choose a or b)

a) replace the I.E.P.

b) add to the I.E.P.

The correct answer is "b" because the informed consent form supplements the I.E.P. A good behavior management program is part of a comprehensive educational plan.

The major behavior management goals for a student should be stated as objectives on the I.E.P. The informed consent document spells out the details of the behavior management goal(s) on the I.E.P. It is necessary to add an informed consent form to the I.E.P. because the I.E.P. does not give all of the information that is required to obtain

full informed consent to use an intrusive training procedure with severe behavior problems.

Here is another question for you.

Are the behavior management goals and plans that are stated on an I.E.P.: (answer a, b or c)

a) sufficient for full informed consent

b) necessary but not enough for full informed consent

c) redundant and not necessary

The behavior management goals and plans on an I.E.P. need to be supplemented with full informed consent materials, so the correct choice is "b".

Necessary Components of an Informed Consent Document

Behavior. The first part of the consent document must describe the problem behavior. The description should be easy to understand. It should state what the problem behavior looks like, when it occurs, how often it occurs, how intense it is, and how long it lasts. Here is an example of a good description of a problem behavior.

1) Problem Behavior

J. Smith tantrums at school. He yells, flails his arms and legs, and throws objects such as chairs, books, and wastebaskets. These tantrums happen an average of twice a day. They usually occur when the teacher is leaving J. in order to work with another student.

This description gives the reader a complete and accurate picture of the problem behavior.

Here's another question for you.

What should the first part of the consent document include? (answer a, b or c)

a) statement of goals

b) description of the problem behavior

c) review of student's history

The first part of the consent document should describe the problem behavior, so the correct answer is "b".

Previous Treatments. The second part of the consent form should provide a brief review of the treatment procedures that have been tried so far. The purpose of the second section is, usually, to demonstrate that less intrusive procedures have already been tried. This second section of the document can be brief. Additional information about the treatment history may be placed in the student's file for referrals;

it's not necessary to explain in detail at this point. Here is an example:

2) Previous Treatments

The student, J. Smith, has previously been treated for tantruming by reinforcement of other behaviors and use of time-out. The data from these treatments is available for review. These treatments did not succeed in significantly reducing the problem behavior.

Here is another question for you.

Why are previous treatments for the problem behavior reviewed on the consent document? (choose, a, b or c)

a) to provide a detailed student history

b) to demonstrate that less intrusive procedures have been tried

c) to document teacher competence with behavioral treatments

Previous treatments are reviewed on the consent form to demonstrate that less intrusive treatments have been tried, so the correct answer is "b".

So far you have learned about the first two sections of an informed consent document. They are:

1) A description of the problem behavior

2) A description of previously attempted treatments

Now let's go on to what the third and fourth sections of a consent document should be.

Proposed Treatment

The third part of the informed consent form should present a clearly worded description of the proposed treatment. Jargon should be avoided whenever possible. The description of the proposed treatment should include an explanation of what will happen to the student during treatment. For example, this third section of the consent document might read:

3) Proposed Treatment

When J. tantrums, the teacher will say, "No yelling!" once in a loud, scolding voice. She will say, "Go to time-out." The time-out room is an office next to the classroom. The room has been emptied for use as a time-out area. A one-way window provides the teacher with viewing access to the room. When J. enters the room, the door will be closed but not locked. The teacher will set a timer for 10 minutes. At the end of that time, J. will be told to "Come back to work." He will be given the same task he was given before the tantrum.

In the event that J. will not voluntarily walk to the time-out room, the teacher and aide will physically move him. They will grasp his shirt at the shoulder seam and his belt below his back and move him. If J. continues to tantrum -- yelling, flailing, or kicking -- after ten

minutes, he will not be released from time-out until he is quiet. If any time-out session goes longer than 45 minutes or if the total time spent in time-out goes over one hour in a single day, the school psychologist will review the treatment.

Here's another question for you.

Should the "Proposed Treatment" section of the consent document include an explanation of <u>all</u> that will happen to a student during treatment? (answer "yes" or "no")

The correct answer is "yes". Everything that will happen during treatment should be described in this section of the consent document.

<u>Risks of Treatment</u>. The fourth section of the consent form should provide a description of the risks involved in the treatment. This section deals with the major, most probable risks only. There is no need to discuss all possible risks. For example, you don't need to say that the student could get hit by lightning because the time-out room has an outdoor window. However, you do need to describe major risks -- such as the possibility that the student could injure himself while alone in time-out. An example of this section of the document might read:

4) Risks of Proposed Treatment

Possible negative side effects are associated with any punishment procedure such as: a) undesirable emotional reactions; b) initially increased tantruming and/or aggression; and c) escape and/or avoidance of the punishing situation.

However, a review of the literature (Koegel & Egel, 1980) shows that in most cases time-out is effective with autistic children and does not create negative side effects. A remote possibility exists that J. could harm himself by hitting, biting or head-banging while in time-out. However, J. will be observed through a one-way mirror so that, in the event of attempted self-injury, he could be stopped.

Here's another question.

Should all possible risks be described in the "Possible Risks" section of the consent document? (answer "yes" or "no")

The correct answer is "no". Only the major likely risks need to be identified in this section of the consent document.

So far you have learned about the first four parts of an informed consent document. These are:

1) A description of the behavior problem

2) A description of previous treatments

3) An explanation of the proposed treatment

4) A description of possible risks when using the proposed treatment

Now let's go on.

Recording Data. The fifth part of the consent document should describe what data will be collected and how data will be recorded. For example:

5) Data Collection

The teacher will record each tantrum. She will record how many tantrums occur each day. She will also record the duration of each tantrum by starting a stop watch when she says, "No yelling, go to time-out," and stopping the watch when the student leaves the time-out room.

Here's a question for you.

Should the consent document describe: (choose a, b or c)

a) type of data collected

b) data collection methods

d) both of the above

The consent document should describe both the types of data to be collected and how data will be collected, so the correct answer is "c".

Expected Outcomes. The sixth section of the consent document should describe the expected behavioral outcome. This section should describe the expected positive results of the treatment in terms of the student's behavior based upon the research literature and professional experience of those providing the treatment. This section should also present a description of what will occur in terms of student behavior after the treatment is stopped. For example:

6) Expected Outcomes

It is expected that J's tantrums will worsen during the first few days of the time-out procedure. After this initial increase, we expect the number of incidents to decline. As J. spends less time tantruming, we expect an increase in the number of skills he will learn such as working by himself. While we are working on reducing J's tantrums, we will be teaching him to work by himself on prevocational tasks. It is

expected that J. will learn to work by himself for longer periods of time. Once the tantrums have become infrequent, we will stop using time-out and use instead a cost response technique.

Here's another question for you.

The "Expected Outcomes" section of the consent document should include descriptions of: (choose a, b or c)

a) how the treatment affects other students

b) what will happen after treatment stops

c) both a and b

The correct answer is 'b". This section of the consent document should include a description of what will happen once treatment stops.

Who Will Do the Treatment? Next, the consent document should name the people who will carry out the treatment program. For example:

7) Treatment Implementor(s)

The teacher Jim Frank and classroom aide, Will James, under the supervision of Betty Langtry, will carry out this treatment program.

Alternative Treatments. The eighth part of an informed consent document lists alternative treatments which might be used, along with an explanation of why they are not being used. The reason for identifying

these other methods is to make sure that a parent or guardian has choices from which to make an informed decision. For example, this third section of an informed consent form might read:

8) Alternative Treatments

1) Sedation -- it is possible that strong tranquilizers could reduce J's tantrums. However, the side effects are likely to interfere with learning by making J. drowsy.

2) Overcorrection -- it is possible that overcorrective exercises could be used to punish the tantruming behavior. However, the I.E.P. team believes that the proposed treatment is less intrusive because overcorrection carries a greater risk of injury.

3) Homebound instruction -- it is possible that J's behavior would be better if he stayed at home. However, his parents want him to go to school and homebound instruction is socially restrictive.

Here's another question for you.

What should the "Alternative Treatments" section of the consent document describe? (choose a or b)

a) ineffective alternative treatments

b) all reasonable) alternative treatments

The eighth section of the informed consent document should describe all reasonable alternative treatments, so the correct choice is "b".

Signature. The final portion of the consent form is the signature of the parent or guardian. This section must include the following elements: a) a statement that the parent has read and understood the information on the consent document; b) a statement that treatment effects cannot be guaranteed; c) a statement giving permission to perform the treatment; d) a statement that consent may be withdrawn at any time; e) the parent/guardian's signature; f) the date; and g) a witness's signature.

The purpose of this final section of the consent form is to document, in writing, the nature of the consent the parent or guardian is giving. The elements of this final section are legal requirements for obtaining valid informed consent.

9) Consent

a) As legal parent(s) or guardian(s) for _____, I/we, (Circle one or both as appropriate) _____, hereby consent to the use of the treatment procedures described on the previous pages of this consent document and on our child's I.E.P.

b) I/We understand that there is no guarantee of success with this treatment, but that it is the best professional effort approach possible at this time.

c) I/We understand that there are some risks in this treatment described on a previous page, and that I/we may withdraw consent at any time verbally or in writing. Although consent can be withdrawn at any time, normally the decision to stop the treatment would be made by all members of the I.E.P. team, including the parent(s) or guardian(s).

d) This form has been fully explained, any related questions have been answered, and I/we understand the contents of this document.

e)

Signature of Parent(s) or Guardian(s)	Signature of Witness
Name of Parent(s) or Guardian(s)	Name and Title of Witness
Date	Date

Sample Informed Consent Document

Informed Consent for Intrusive Behavioral Treatments

Name of Student:

1) Problem Behavior:

2) Previously Attempted Treatments:

3) Proposed Treatments:

4) Risks of Proposed Treatments:

5) Data Collection Procedure

6) Expected Outcomes:

7) Treatment Implementor(s):

8) Alternative Treatments:

9) Consent

a) As legal parent(s) or guardian(s) for _____, I/we, (circle one or both as appropriate) _____, hereby consent to the use of the treatment procedures described on the previous pages of this consent document and on our child's I.E.P.

b) I/We understand that there is no guarantee of success with this treatment, but that it is the best professional effort approach possible at this time.

c) I/We understand that there are some risks in this treatment described on a previous page, and that I/we may withdraw consent at any time verbally or in writing. Although consent can be withdrawn at any time, normally the decision to stop the treatment would be made by all members of the I.E.P. team, including the parent(s) or guardian(s).

d) This form has been fully explained, any related questions have been answered, and I/we understand the contents of this document.

e)

Signature of Parent(s) or Guardian(s)	Signature of Witness
Name of Parent(s) or Guardian(s)	Name and Title of Witness
Date	Date